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REVIEW

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# Goal adjustment by people living with long-term conditions: A scoping review of literature published from January 2007 to June 2018.

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**ABSTRACT**

Long-term health conditions can limit achievement of personal goals. We aimed to map and synthesize definitions of goal adjustment, theoretical underpinnings, associations with recovery and supportive interventions for adults with long-term conditions. We searched multiple databases (January 2007–June 2018) and identified peer-reviewed research relating to goal adjustment. Data were charted, mapped and synthesized using content analysis and descriptive summaries. Two stakeholder consultations informed the review. Ninety-one articles were included. A range of long-term conditions were represented including cancer (22%), stroke (12%) and mixed neurological conditions (8%). Goal adjustment was one available option when faced with unattainable goals; other options were goal disengagement and goal re-engagement. Most studies were quantitative (58%), reporting mainly positive associations between goal adjustment, disengagement, reengagement and recovery. The Dual Process Model, Goal Adjustment Model and Self-Regulation Theory were most cited underpinning models/theory. Five interventions were identified; only one (self-system therapy) was evaluated in a randomized controlled trial. Our review provides original and significant insights into goal adjustment definitions, theoretical underpinnings and association with recovery. Effective interventions to support goal adjustment, disengagement and reengagement are lacking. This research-practice gap warrants attention to ensure people with long-term conditions are optimally supported when facing unattainable goals.

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## Background

A long-term condition can be defined as a health condition lasting one year or longer and having an impact on a person's everyday life (The Scottish Government, 2015). The worldwide prevalence of long-term conditions is increasing (Gallacher et al., 2019). In the UK, the management of long-term conditions is a "central task" of the NHS and accounts for 70% of the health service budget (NHS England, 2014). Long-term conditions have a considerable impact on the people who live with them, and are associated with a range of physical, emotional, sensory and cognitive problems (Coulter et al., 2015). Many people live with two or more long-term conditions (The Scottish Government, 2015). Mental health problems become more evident as the number of physical conditions increase (Barnett et al., 2012).

The term "goal" is conceptually broad (Carver & Scheier, 1998, Chap. 5). In health contexts, goals are categorized in many different (and potentially overlapping) ways according to their contextual, structural, functional, and temporal characteristics (Mann et al., 2013; Ogbeiwi, 2018). For example, personal goals, life goals, rehabilitations goals, health goals, self-management goals, long-term goals and short-term goals are terms commonly used in long-term health conditions literature. A "rehabilitation goal" is defined as, "a desired future state to be achieved by a person with a disability as a result of rehabilitation activities" (Levack & Siegert, 2014, 11). However, within the rehabilitation literature, other terms are used, for example "life goals" defined as, "desired states that people seek to obtain, maintain or avoid" (Nair, 2003). Due to this heterogeneity in the use of goal-related terms, we sought a general definition of "goal" not aligned with any particular professional group, long-term condition or health context. We therefore used the Oxford English dictionary definition of goal, "The object of a person's ambition or effort; an aim or desired result" (The Oxford English Dictionary).

A long-term condition can threaten an individual's ability to achieve their personal goals. Ongoing pursuit of unattainable goals can negatively impact on psychological wellbeing and prevent redirection of efforts towards goals that are achievable (Rasmussen et al., 2006; Wrosch et al., 2003a). However, adjusting goals can positively impact on the recovery and wellbeing of people with a variety of long-term conditions including stroke (Brands et al., 2015; Wood., 2010), lower limb amputation (Coffey et al., 2014b), cancer (Janse et al., 2016c; Wrosch & Sabiston, 2013) and arthritis (Arends et al., 2016).

We conducted a broad preliminary search of the literature using the key word "goal" to identify existing reviews (of any type) focusing on the topic of goal adjustment for people living with long-term conditions. We understood goal adjustment to be any *alteration* or *change* to a personal goal. The following data bases were searched from 2007 to 2017: Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports; Cochrane Database of

Systematic Reviews, PROSPERO, CINAHL, PubMed, EPPI, and Epistemonikos using the keyword "goal." No reviews were identified focusing on goal adjustment. Although we found a number of reviews focusing on goal setting in rehabilitation (Levack et al., 2015; Rosewilliam et al., 2011; Sugavanam et al., 2013) and self-management contexts (Lenzen et al., 2017); none referred to goal adjustment. This preliminary search further highlighted variability in use of goal-related terms. Within rehabilitation contexts, goal setting was defined as, "the establishment or negotiation of rehabilitation goals" (Levack et al., 2015). However, in self -management contexts, goal setting was defined as "a process in which healthcare professionals and patients agree on health related goals" (Lenzen et al., 2017).

The findings of our preliminary search highlighted that (i) there is currently a lack of attention to the concept of goal adjustment in the literature, with variable use of goal-related terminology (ii) available evidence has not been comprehensively mapped or summarized; therefore (iii) implications for research and practice are unclear.

### *Aim*

To systematically locate, review and summarize the available literature on goal adjustment by people with long-term conditions in order to identify research gaps and consider implications for practice.

### *Research questions*

RQ1. Is goal adjustment defined within the literature, and if so how?
RQ2. Is goal adjustment underpinned by any theories, models or frameworks, and if so which?
RQ3. Is there evidence of an association between goal adjustment and recovery or well-being?
RQ4. What interventions, strategies or approaches have been reported to support goal adjustment?

## Methodology

Scoping reviews are ideally suited to exploring, mapping and synthesizing existing knowledge within a topic area and identifying knowledge gaps (Colquhoun et al., 2014; Tricco et al., 2018). We therefore opted to conduct a scoping review of the goal adjustment literature. Conduct and reporting of the review was informed by Arksey & O'Malley's Scoping Study Framework (Arksey & O'Malley, 2005) and the PRISMA extension for Scoping Reviews (PRISMA-ScR) (Tricco et al., 2018). Two stakeholder involvement meetings were incorporated into the review to enhance the quality, relevance and impact of our findings (Pollock et al., 2019). As recommended in scoping reviews, an iterative

decision-making approach was employed throughout the review process (Levac et al., 2010).

### *Stakeholder involvement*

Involvement of stakeholders is essential to enhance the quality, relevance and usefulness of research (Boaz et al., 2018; Brett et al., 2014; Pollock et al., 2019). There are different ways to involve stakeholders in research. Although there is no consensus about which methods are best, use of face-to-face meetings has been identified as a key approach to involving stakeholders in decision making and the generation of key messages when conducting reviews (Pollock et al., 2018).

Stakeholders were involved at two stages of the review process to address RQ1 and RQ4. Stakeholders were recruited from a Scottish community rehabilitation team and included: four people with one or more long-term condition (including stroke, arthritis, visual deficits, cerebrovascular disease, anxiety and depression), a carer and four health professionals (including an occupational therapist, physiotherapist, nurse and rehabilitation assistant) experienced in working with people with a variety long-term conditions. Stakeholders took part in two face-to-face meetings, supplemented with written communication (See Supplementary file 1 & 2). The organization, structure and conduct of meetings were informed by a published example of co-production of a systematic review (Pollock et al., 2015) and by the National Institute of Health Research INVOLVE recommendations (National Institute of Health Research). The aim of the first meeting was to present and discuss extracted definitions of goal adjustment with stakeholders, and to identify a "Top 5" for potential inclusion in a goal adjustment definition (RQ1). The aim of the second meeting was to review identified intervention, strategies and approaches with stakeholders, then rate their "helpfulness" in relation to facilitating goal adjustment (RQ4). Specific group ranking and rating tasks were used within each involvement meeting to stimulate discussion and decision-making.

### *Search Strategy*

As there were uncertainties about terminology used in the goal adjustment literature, and in order to ensure efficient retrieval of relevant papers, we adopted an inclusive, staged approach to searching. For example, in our efforts be to inclusive, our search strategy included the term "setting," to support the identification of papers which potentially referred to a goal adjustment as part of a process of goal setting. Our search strategy involved conducting three separate, interrelated searches, each building on the previous searches. Key decisions were made in a series of pre-planned team meetings. Details of

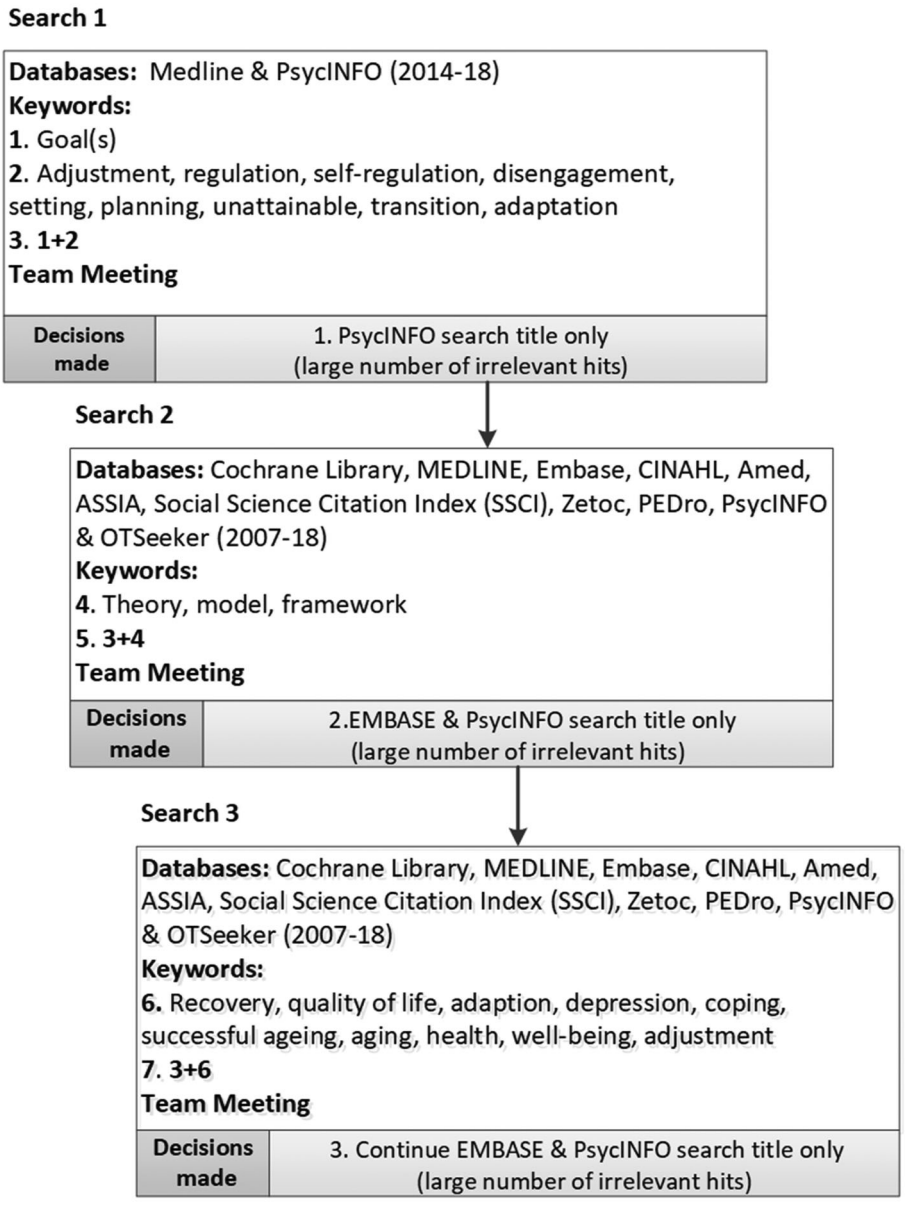


**Figure 1.** Staged and strategy.

these searches, including keywords and iterative decision-making, are provided in Figure 1. Databases searched included Cochrane Library, MEDLINE, Embase, CINAHL, Amed, ASSIA, SSCI, Zetoc, PEDro, PsycINFO and OTSeeker. Searches were from January 2007 to June 2018. We selected 2007 as the start date as our preliminary search had not identified any potentially relevant literature before this date. We understood that our staged approach to searching would allow this date to be adjusted if deemed necessary. Reference lists of included

articles were searched (with no date restrictions) to identify additional studies which met the inclusion criteria.

### Inclusion criteria

Due to the nature of this review, an inclusive approach to the goal adjustment literature was adopted throughout all three searches. Inclusion criteria were identified in relation to (i) sources of evidence, (ii) participants and (iii) concept.

#### (i) Sources of evidence

We included any peer-reviewed, full text articles written in English regardless of research design, in order to capture all types of evidence (for example, including discussion papers, literature reviews, systematic reviews, theoretical papers, quantitative studies, mixed methods and qualitative studies). Articles only containing abstracts were excluded.

#### (ii) Participants

We included articles with participants aged 18 years and older, with a long-term condition, defined as a health condition lasting one year or longer and having an impact on a person's everyday life (The Scottish Government, 2015). Studies that discussed goal adjustment without reference to people with long-term conditions were excluded.

#### (iii) Concept

For the purposes of article selection, we maintained our dictionary definition of goal, "The object of a person's ambition or effort; an aim or desired result" (The Oxford English Dictionary). At this stage in the review process, we defined goal adjustment as *an alteration or change* to a personal goal. We included studies detailing goal adjustment in any given context (for example, in everyday life, rehabilitation or self-management contexts). Due to the noted variability in definitions of goal setting, and to avoid alignment with any particular professional group or health context, we used a dictionary definition of goal setting, "the process of deciding what you want to achieve over a particular period" (Cambridge University Press, 2020). Studies focusing on goal setting with no reference to goal adjustment were excluded.

### Identification of relevant studies

Following removal of duplicates, one reviewer (KT) screened the titles and abstracts of all identified articles based on broad eligibility criteria and excluded those that were obviously irrelevant. To reduce the likelihood of bias, two reviewers (KT & LS) then independently reviewed all remaining articles based on the specific eligibility criteria for each search. All abstracts and, if necessary,

full texts of remaining articles were read and independently categorized as "include", "exclude," or "unsure." Those articles categorized differently or as "unsure" were discussed, with reference to the full text if necessary, until agreement was reached. Where there was still uncertainty (two articles), a third reviewer's (JE) opinion was sought allowing consensus to be reached.

### *Quality of evidence*

No formal assessment of methodological quality of included studies was performed; this follows recommended practice for scoping reviews, where the aim is to provide an overview of all existing evidence regardless of quality (Peters et al., 2015).

### *Data extraction and charting*

One reviewer (KT) extracted data using data charting tables that had been piloted in the protocol development stage. Relevant data from all included studies were concurrently extracted onto one or more of the following data charting tables:

- **Table 1:** To chart **core data** (including author(s), country, publication date, study type, aims and population) from all included studies to provide a broad map of the evidence.
- **Table 2**: To chart **definitions** of goal adjustment or its key components (including citing references).
- **Table 3:** To chart key **theories, frameworks, or models** underpinning goal adjustment (including author(s), name and description of theory, framework or model).
- **Table 4:** To chart **associations** identified between goal adjustment and recovery or well-being (including author(s), study population, nature and direction of association with summary findings).
- **Table 5:** To chart **interventions, strategies, or approaches** reported to support the goal adjustment process (including author(s) and description of intervention or strategy).

A second reviewer (LS) independently reviewed data in each charting table. Any edits and/or additions to extracted data were discussed and agreed (KT,LS).

### *Evidence mapping*

To provide a broad map of the goal adjustment literature, core data from all included articles were summarized using descriptive statistics, graphs and narrative summaries.

### *Data synthesis*

Four separate syntheses, linked to each specific research question, were conducted. Data from stakeholder involvement meetings were included in synthesis 1 and 4.

**Synthesis 1 (RQ1)**: A definition of goal adjustment was informed by content analysis (Hsieh & Shannon, 2005) of extracted definitions and feedback from our first stakeholder involvement meeting. We used a conventional approach to content analysis as this is best suited to exploring meanings from existing data (Hsieh & Shannon, 2005). To get a shared sense of the whole data set, two researchers (KT, LS) independently read and then discussed extracted data related to goal adjustment definitions and/or its key components. Exact words or phrases capturing key concepts and terms used within the data were then highlighted and collated (KT). Collated data was then jointly reviewed, discussed, coded and categorised (LS,KT). During this iterative process, any differing opinions about coding or categorisation were resolved through a process of discussion to consensus (LS, KT). In the final stage of analysis, relationships between categories of definitions were identified (KT, LS). The "Top 5" goal adjustment definitions identified by the stakeholder group were then mapped onto identified categories to ensure their relevance. Findings from the content analysis and stakeholder involvement meeting were reviewed and discussed in a team meeting to agree definition(s).

**Synthesis 2 (RQ2):** Extracted accounts of theories, frameworks, or models underpinning goal adjustment were summarised (KT), checked (LS) and any edits or additions agreed (LS, KT). Key articles relevant to each theory, framework or model were identified from reference lists of included studies. These were reviewed to check descriptive summaries for accuracy. As the aim of this synthesis was to provide descriptive summaries; the development, conceptual integrity, predictive or explanatory value of included theories, models and frameworks were not critiqued.

**Synthesis 3 (RQ3):** Extracted data describing associations between goal adjustment and recovery and /or wellbeing were tabulated by one reviewer (KT) under the headings of (i) association variables, (ii) direction of association – *positive* (improvement in recovery and/or wellbeing variables), *negative* (deterioration in recovery and/or wellbeing variables) or *neutral* (no change in recovery and/or wellbeing variables), (iii) description of association and (iv) other relevant information. All tabulated data was independently checked (LS). Any edits and/or additions to extracted data were discussed and agreed (KT,LS).

**Synthesis 4 (RQ4):** Descriptions of interventions reported to support the goal adjustment process were tabulated using TIDieR checklist (Hoffmann et al., 2014). Descriptions of strategies or approaches reported to support the goal adjustment process were categorised and tabulated separately under the headings of – citing reference, study type, strategy and/or approach, long-term condition and link to goal adjustment. Stakeholder ratings of "helpful" and "unhelpful" interventions, strategies and approaches were integrated with review findings.

## Results

We screened 8459 records and considered the full-texts of 186; from these we identified 91 articles for inclusion in the scoping review. See Figure 2 for

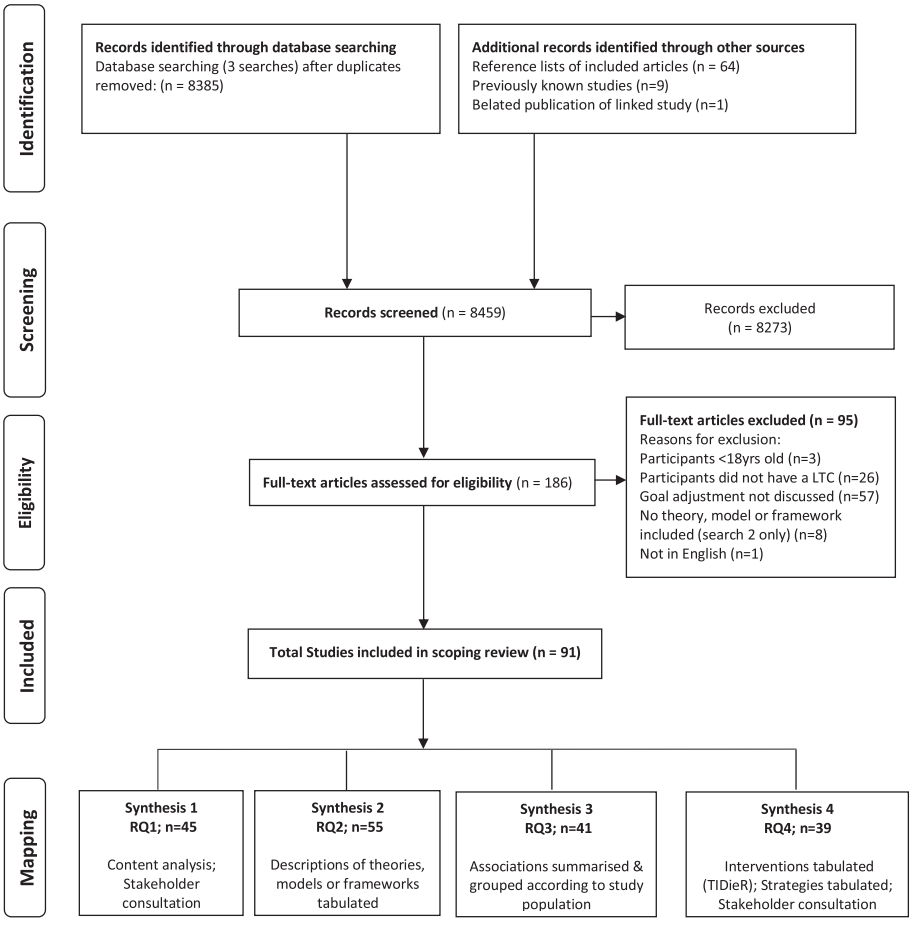


**Figure 2.** PRISMA diagram: articles included at each stage of the review process.

PRISMA diagram detailing articles included at each stage of the review process and Supplementary File 3 for table of included studies (with full reference list).

## *Mapping of goal adjustment literature*

Over 90% of the included articles were from the Netherlands ($n = 29$), USA ($n = 16$), UK ($n = 11$), Germany ($n = 7$) and Ireland ($n = 5$). Studies included people with a wide range of long-term conditions (see Figure 3), the most common being cancer ($n = 23$; 25%) followed by stroke ($n = 11$; 12%). Less than 10% of included articles ($n = 6$) included participants with mental health conditions. Most articles were published from 2010 to 2018. A range of methodological approaches were employed, the most common being quantitative ($n = 53$; 58%), followed by qualitative ($n = 13$; 14%), mixed methods ($n = 11$; 12%) and literature review ($n = 6$; 7%). The remaining articles included discussion papers ($n = 7$; 8%) and

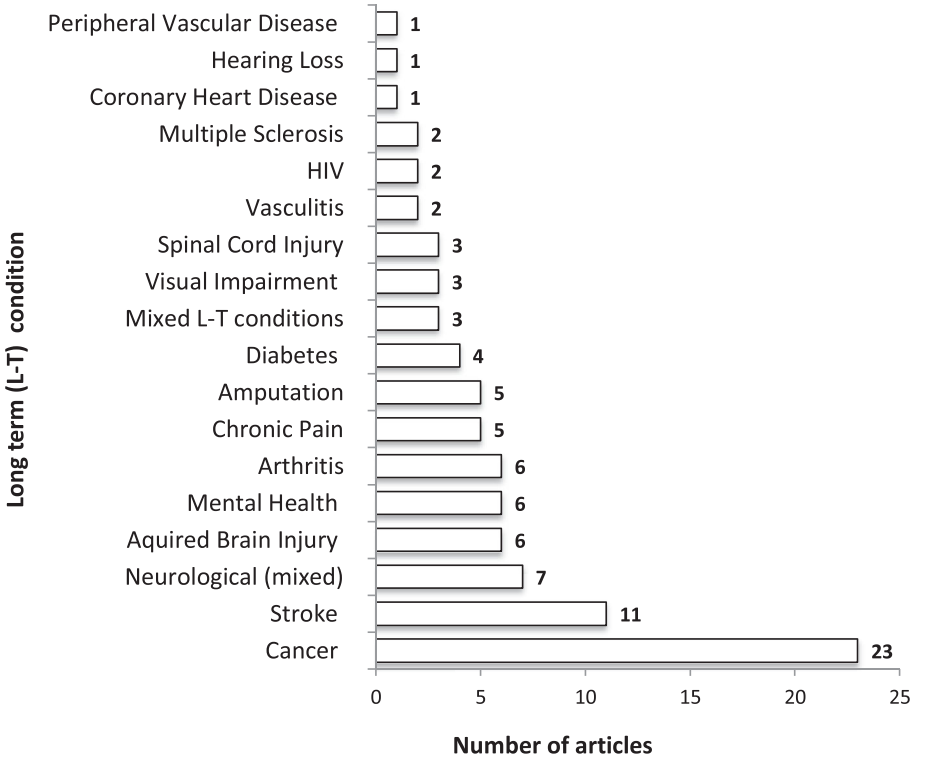


**Figure 3.** Study populations.

one theoretical paper ($n = 1$; 1%) (See Supplementary file 3 – Table of included studies; "study type" column).

Of the **quantitative studies** included in the review ($n = 53$), the vast majority ($n = 43$ /53; 81%) broadly aimed to investigate associations between goal adjustment and other wellbeing and/or quality of life variables. Three studies ($n = 3$/53; 6%) described evaluations of intervention effectiveness. The first was a protocol for randomized controlled trial of a psycho-educational programme (Right on Target) (Arends et al., 2013). The second evaluated the Right on Target intervention using a quasi-experimental design (Arends et al., 2018), and the third evaluated a psychological intervention (Self-system therapy) using a randomized controlled trial design (Eddington et al., 2015). The aims of the remaining quantitative studies ($n = 7$; 13%) were varied. Two compared goal strategies of people with depression with healthy controls (Dickson et al., 2016; Koppe & Rothermund, 2017); another compared goal differences between people with cancer and healthy controls (Pinquart et al., 2008). Two investigated changes to goals over time and adjustment strategies used in people with cancer (Janse et al., 2015, 2016a). One was a survey of goal-setting education practices of diabetes educators (Malemute et al., 2011) and the final study evaluated the psychometric properties of the Coping Inventory for Stressful Situations (Brands et al., 2014).

Aims of the **qualitative studies** ($n = 13$) fell into three broad categories. Most ($n = 9/13$; 69%) aimed to investigate experiences of the goal setting process from the perspective of people with long-term conditions (Baird et al., 2010; Brown et al., 2014), staff delivering their care (Fleming et al., 2013; Hunt et al., 2015; Leach et al., 2010) or both (Barnard et al., 2010; Lawler et al., 1999; Ohman & Asaba, 2009). Three qualitative studies (23%) investigated goal adjustment strategies used by people with cancer (Janse et al., 2016b; Stefanic et al., 2015) and lower limb amputation (Dunne et al., 2014). The remaining qualitative study (8%) investigated the process of community integration from a stroke survivor perspective (Jennifer et al., 2010).

Aims of the *mixed methods studies* ($n = 11$) could be broadly categorized as: intervention development (Arends et al., 2015, 2017; Scobbie et al., 2011), process evaluation (Lyons et al., 2018; McPherson et al., 2009; Scobbie et al., 2013); understanding the process of goal adjustment in different long-term conditions (Boerner & Cimarolli, 2005; Boerner & Wang, 2012; Crombez et al., 2016; Hoyt et al., 2016) and investigating goal setting issues in neurological rehabilitation (Playford et al., 2009).

Aims of the *discussion papers* ($n = 7$) were also varied. Two focused on the topic of goal dysregulation in people with bipolar disorder (Johnson, 2005; Johnson et al., 2012). Two discussed theories and their application to the goal setting process in rehabilitation contexts (Hart & Evans, 2006; Siegert & Taylor, 2004). Two discussed the process of client-centred goal setting with people with aphasia (Hersh et al., 2012) and spinal cord injury (Williams, 2006). The final discussion paper explored processes of change in cognitive–behavioural therapies for chronic pain within the context of goal pursuit (Schrooten et al., 2012).

The aims of *literature reviews* included ($n = 6$) were wide ranging. Two aimed to review the literature on life goals relevant to cancer (Hullmann et al., 2016) and to rehabilitation (Nair, 2003). Two reviewed the goal setting literature in diabetes care (Miller & Bauman, 2014) and in stroke rehabilitation (Rosewilliam et al., 2011). The remaining reviews aimed to define the concept of "optimum function" in people with heart failure (Goodman et al., 2016) and to review theories of behaviour change relevant to goal setting in rehabilitation settings (Scobbie & Wykes, 2009).

The final *theoretical paper* aimed to describe the development of a model of the adaptation process following acquired brain injury (Brands et al., 2012).

## *Synthesis of the goal adjustment literature*

### *Synthesis 1 (RQ1): Is goal adjustment defined within the literature, and if so how?*

Forty-nine percent ($n = 45/91$) of studies included definitions relevant to goal adjustment. Our findings highlighted that goal adjustment is just one of three

available response options when goal attainment is threatened. The second option, goal disengagement, results in the goal being abandoned (even on a temporary basis) rather than adjusted. Goal disengagement may be followed by a third option, goal re-engagement, which involves identification and pursuit of a new (or reprioritised) goal. The studies also highlighted goal maintenance as an available option when there is no, or minimal, threat to goal attainment. Definitions of available goal response options and underlying concepts are summarized in Figure 4.

In the next section, we defined and described each goal response option when goal attainment is threatened based on data synthesized from included studies. Final definitions chosen are those endorsed by the stakeholder group.

***Goal adjustment.*** Goal adjustment can be defined as, "*adjusting a goal to make it achievable.*" It occurs when changes to an individual's personal capacity or situation renders a goal unachievable. The nature of the goal – performance discrepancy (i.e., the difference between what *needs* to happen to achieve the goal and what *can* happen) will determine adjustments made. Goal adjustment typically involves acceptance of, and adjustment to, loss and limitation. Each Individual's goal adjustment capacity may differ. See Supplementary File 4 for key concepts and citing references underpinning the proposed definition of goal adjustment.

***Goal disengagement.*** Goal disengagement can be defined as, "*letting go of the goal.*" It involves withdrawing effort and commitment to a goal that is no longer attainable, even if adjustments were made. Resources are released or "freed up" to consider and pursue other achievable goals. Refocusing resources on new goals can enhance psychological wellbeing. Goal disengagement can

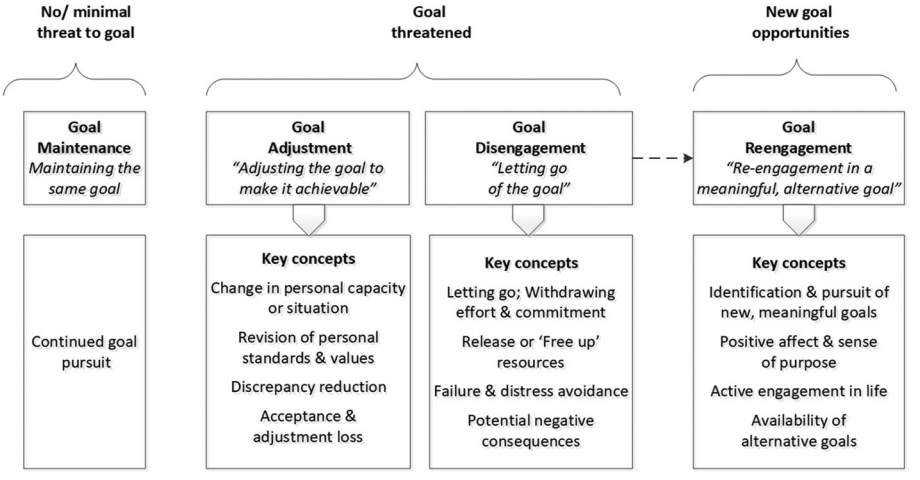


**Figure 4.** Defining goal response options.

remove the negative emotional consequences of repeated failure. Availability of alternative goals is an important aspect of adaptive goal disengagement. See Supplementary File 5 for key concepts and citing references underpinning the proposed definition of goal disengagement.

***Goal re-engagement.*** Goal re-engagement can be defined as "*re-engaging in a meaningful, alternative goal.*" Alternative goals can be new or previously held goals that are now considered important. The process of goal re-engagement can increase positive affect and create a sense of purpose as the individual returns to being actively engaged in their life. Successful goal re-engagement can depend on personal characteristics and the availability of alternative goals. See Supplementary File 6 for key concepts and citing references underpinning the proposed definition of goal re-engagement.

### *Synthesis 2 (RQ2): Is goal adjustment underpinned by theories, models or frameworks within the literature, if so which?*

Seventy-six percent ($n = 69/91$) of the included studies reported a total of 47 theories, models or frameworks relevant to goal adjustment, disengagement and/or reengagement. To focus the synthesis, each reported theory, model or framework was further categorized into one of two groups (KT, LS). Group 1 included those where a *direct link* had been made between the reported theory, model or framework and goal adjustment within the citing article ($n = 22$). Group 2 included those where *no direct link* had been made between the reported theory, model or framework and goal adjustment within the citing article ($n = 25$). Each group was tabulated separately, then reviewed and approved in the team meeting. Group 1 theories and models are summarized in Supplementary File 7. Those included in Group 2 were not included in the synthesis (see Supplementary File 8).

Fifty-five studies reported a total of 11 theories and 11 models that were included in Group 1. Of these, two models and one theory were reported significantly more often than all others. These were: (i) the dual process model of assimilative and accommodative coping (Brandtstädter & Rothermund, 2002), (ii) the goal adjustment model (Wrosch et al., 2003b) and (iii) self-regulation theory (Carver & Scheier, 1998). The dual process model described two available goal options – *tenacious goal pursuit* and *flexible goal adjustment*. The former is most adaptive when goals are within reach and attainable; the latter when goals are not attainable. The goal adjustment model described a further two available goal options when faced with unattainable goals – *goal disengagement* and *goal reengagement*. Self-regulation theory proposes that a perceived goal-performance discrepancy will determine whether the goal is *maintained*, *modified* or *disengaged* from.

The other reported theories and models were heterogeneous in nature. Three could broadly be described as rehabilitation models or theories – Life goal

rehabilitation model (Nair, 2003), Model of the adaption process (Brands et al., 2012) and Theory of the process of community integration (Wood et al., 2010). The remainder could broadly be described as psychological theories or models.

### *Synthesis 3 (RQ3). Is there evidence of an association between goal adjustment and recovery and/or well-being?*

Fifty-nine percent of the included studies (54/91) reported associations between goal adjustment, disengagement and/or reengagement and recovery and/or wellbeing variables. Due to the descriptive nature of data included within some studies, it was agreed in a team meeting that only empirical data reporting an explicit link between goal adjustment and recovery and/or wellbeing should be included. Subsequently, data from 13 studies were excluded from the synthesis (See Supplementary File 9).

The remaining 41 studies examined a total of 62 associations between goal adjustment, disengagement, reengagement and recovery and/or wellbeing variables. Twenty were cross sectional studies, 20 were prospective cohort studies (ranging from 6 months to 9 years follow up) and one was a quasi-experimental study (See Supplementary File 10). Of the 62 associations investigated; 21 were between *goal adjustment* and recovery and/or wellbeing variables; 19 were between *goal disengagement* and recovery and/or wellbeing variables and 22 were between *goal reengagement* and recovery and/or wellbeing variables. Seventy-nine percent of the associations were positive (improvement in recovery and/or wellbeing); 5% were negative (reduction in recovery and/or wellbeing variables) and 16% were neutral (no change in recovery and/or wellbeing). See Table 1 for details of positive, negative and neutral associations. Three prospective cohort studies with the longest follow-up periods ($\geq$ 5 years) reported positive associations between goal adjustment and depression (Bailly et al., 2016); goal adjustment and improved wellbeing (Hall et al., 2010), (Martinent et al., 2017) and goal disengagement and improved physical health, in populations with mixed long-terms conditions.

*Positive Associations:* Forty-nine positive associations were reported between goal adjustment, disengagement and reengagement and recovery and/or wellbeing variables, over a range of long-term conditions, in both prospective clinical cohort and cross sectional studies. In the majority of studies, positive associations were reported in relation to psychological wellbeing ($n = 29$; 60%) and quality of

**Table 1.** Summary of positive, negative and neutral associations.

| Direction of association (with recovery/ wellbeing variable) | Goal Adjustment associations (n) | Goal Disengagement associations (n) | Goal Reengagement associations (n) | Total Associations (Number; %) |
|---|---|---|---|---|
| Positive | 21 | 10 | 18 | 49 (79%) |
| Negative | 0 | 2 | 1 | 3 (5%) |
| Neutral | 0 | 7 | 3 | 10 (16%) |
| Key: *n* = number; % = percentage | | | | 62 (100%) |

life ($n = 10$; 20%). The remaining studies reported positive associations with physical health ($n = 4$; 8%) and other variables ($n = 6$; 12%) including biomarkers such as inflammation.

*Negative Associations:* Three negative associations were reported. Goal disengagement was associated with increased depression in participants with multiple sclerosis when accompanied by low reengagement (Neter et al., 2009); and with increased negative affect and activity avoidance in participants with chronic pain who scored high on pessimism (Esteve et al., 2018). A negative association was found between goal reengagement and adjustment in people with lower limb amputation (Coffey et al., 2014a). The authors noted that this was contrary to expected findings and diverged from the literature where goal reengagement has repeatedly been linked with greater positive affect.

*Neutral Associations:* Seven studies reported neutral associations between goal disengagement and health and/or wellbeing variables. Four were in people with cancer (Mens & Scheier, 2016; Schroevers et al., 2008; Thompson et al., 2013; Zhu et al., 2015); one in people with myocardial infarction (Garnefski et al., 2009b), one in people with arthritis (Arends et al., 2018) and one in people with vasculitis (Mayor, 2018). Three studies reported neutral associations between goal reengagement and recovery and /or wellbeing variables; one in people with cancer (Zhu et al., 2015), one in people with arthritis (Arends et al., 2018) and the final one in people with vasculitis (Mayor, 2018). With the exception of one (Mayor, 2018), all studies reporting neutral associations also reported positive associations. For example, Mens and Scheier (2016) reported a neutral association between disengagement and wellbeing, but positive between goal reengagement and wellbeing. Zhu et al. (2015) reported a neutral association between disengagement and depression and fatigue; but a positive association between goal disengagement and anxiety.

### *Synthesis 4 (RQ4): What interventions, strategies or approaches have been reported to support goal adjustment?*

Fifty-five percent of included studies ($n = 50/91$) reported interventions, strategies or approaches to support goal adjustment, disengagement and /or reengagement. Twelve of these studies were excluded from the synthesis as they did not make an explicit link between the reported intervention, strategy or approach and how it would support goal adjustment, disengagement or reengagement (Baird et al., 2010; Brown et al., 2014; Garnefski & Kraaij, 2012; Garnefski et al., 2009a, 2009b, 2010; Kraaij et al., 2008; Levack et al., 2011; McPherson et al., 2009; Ohman & Asaba, 2009; Playford et al., 2009; Rosewilliam et al., 2011). Of the 38 remaining studies, eight reported *interventions* and 25 reported *strategies and/or approaches* to support the goal adjustment process. During the synthesis process, we became aware of a sub-set of studies ($n = 5$) that reported *patient centred* versus *staff led* strategies and approaches to support goal adjustment. These studies were tabulated separately as (unlike

other included studies) goal adjustment was considered at the goal setting, rather than goal pursuit stage.

***Interventions reported to support the goal adjustment process.*** Nine percent (*n* = 8/91) of included studies described a total of five interventions reported to support goal adjustment, disengagement and /or reengagement (see Supplementary File 11). Two interventions, the *Goal Setting and Action Planning framework* (Scobbie et al., 2011, 2013) and the *SMARTER goal setting framework* (Hersh et al., 2012)*, were* designed to inform goal setting practice with stroke survivors in rehabilitation settings. Both include an explicit appraisal and shared decision-making stage, thus enabling ongoing goal adjustment, disengagement and reengagement options to be considered. The "E" in the SMARTER framework denotes "evolving", acknowledging that goals can be fluid, changing and dynamic. *The Health Through Activity programme* (Lyons et al., 2018) is an educational, goal based, intervention. The need for goal adjustment, disengagement and reengagement is considered in a weekly goal review. *Right on Target* (Arends et al., 2013, 2018) is a group-based psychosocial educational programme. It is designed to enhance participants' awareness of, and response to, threatened personal goals. Finally, *Self-System therapy* (Eddington et al., 2015) is a psychological intervention delivered to people with depression. It is designed to identify and correct deficiencies in goal pursuit. The effectiveness of only one of these interventions (self-system therapy) was evaluated using a randomized controlled trial (Eddington et al., 2015). People with depression were randomly assigned to either self-system therapy (intervention) or cognitive behavioural therapy (comparison). The interventions were found to be equally effective in improving depression. Goal disengagement did not moderate the effect of treatment condition on change in depression scores or have any other significant effects. However, goal reengagement did significantly moderate the effect of treatment condition on change in depression scores. People low in goal reengagement benefitted more from self-system therapy than cognitive behavioural therapy. In contrast, people high in goal reengagement benefitted equally from both interventions.

***Strategies and/or approaches reported to support the goal adjustment process.*** Twenty-seven percent (*n* = 25/91) of included studies suggested strategies and/or approaches to support the goal adjustment process (see Supplementary File 12). These could be broadly categorized under the following headings: "psychological interventions"; "strategies used by people with long-term conditions"; "rehabilitation approaches", "education & training" and "other".

*Psychological interventions*: Ten studies suggested six psychological interventions or approaches to support goal adjustment. These were (i) cognitive behavioural therapy (or cognitive approaches) (Esteve et al., 2018; Johnson et al., 2012; Schroevers et al., 2011; Schrooten et al., 2012; Van Damme et al., 2016); (ii)

acceptance and commitment therapy (Ciere et al., 2017; Coffey et al., 2014a; Schrooten et al., 2012; Thompson et al., 2013); (iii) motivational interviewing (Hart & Evans, 2006; Johnson et al., 2012; Schrooten et al., 2012); (iv) mindfulness (Schroevers et al., 2008, 2011; Schrooten et al., 2012); (v) mental contrasting (Hart & Evans, 2006) and (vi) clarification orientated interventions (Schrooten et al., 2012). All suggestions were made in discussion of study findings or relevant literature, rather than empirical evidence of effectiveness of any particular psychological intervention.

*Strategies used by people with long-term conditions:* Five studies, using qualitative or mixed method designs, investigated and reported strategies used by people with specific long-term conditions to support goal adjustment. These are summarized in Table 2.

*Rehabilitation approaches:* Following a review of life goals literature, Nair (2003) recommended that rehabilitation should seek to identify patients' life goals, and support them with the loss of unattainable life goals and development of attainable ones. Boerner and Cimarolli (2005) suggested the life goal approach recommended by (Nair, 2003) should be integrated in visual rehabilitation. Finally, Von Blackenburg et al. (2014) recommended integration of life goal adjustment into cancer rehabilitation services to enhance adaptive self-regulation and quality of life.

*Education and training:* Four studies recommended (i) training people with brain injury in self-monitoring, evaluation and goal disengagement and reengagement (Hart & Evans, 2006), (ii) providing information and training to patients with head and neck cancer (and their partners) to engage in attainable life goals (Offerman et al., 2010), (iii) providing coping skills training (including goal adjustment coping) to people with diabetes (Kraaij & Garnefski, 2015) and (iv) proving

**Table 2.** Strategies used by people with long-term conditions to support goal adjustment.

| Long-term condition | Strategies used to support goal adjustment |
|---|---|
| Colorectal cancer (Janse et al., 2016a, 2016b) | *Goal strategies:* 1. Shifting priorities across life goal domains; 2. Scaling goals back in the same life domain 3. Scaling goals up in the same life domain 4. Form shorter-term goal, 5. Form longer-term goal, 6. Put goal on hold, 7. Continue to pursue disturbed goals and 8. Give up goal commitment without adopting a new goal |
| Lower limb amputation (Dunne et al., 2014) | 1. *Interpersonal strategies* – accepting help from others, seeking support/ assurance from fellow patients & emotional support from friends/ family. 2. *Strategies to manage limitations* – adjusting goals to constraints, maintaining a positive outlook, sense of humour, de-emphasizing the impact of amputation, realising there are others worse off and accepting limitations. 3. *Meaning-making strategies* – involved higher-order cognitive strategies used to accommodate goal disruption into the broader context of life as a whole; benefit finding and re-orientation |
| Visual impairment (Boerner & Wang, 2012). | *Psychological strategies*: 1. Concentrate on the positive, 2. Accept what cannot be changed, 3. Motivational self-talk, 4. Acknowledge I cannot do it, 5. Acknowledge other people are worse off, 6. Try not to think about it, 7. Rationalize to self why some activities are no longer do-able, 8. Seek distraction, 9. Positive attitude toward using help, 10. Use sense of humour, 11. Trust in support from others, 12. Get encouragement from how others cope |

education and training about goal adjustment and emotional regulation to people with cancer (Bahrami et al., 2017). All recommendations were made in the discussion of study findings or relevant literature, rather than empirical evidence of effectiveness of any particular education and /or training intervention.

*Other:* Four studies recommended "other" strategies and/or approaches to support the goal adjustment process. This included *peer support* for patients with newly acquired disabilities (such as spinal injury) to support adaption and adjustment of life goals (Williams, 2006); use of *vignettes* to understand how patients with arthritis cope with threatened goals (Arends et al., 2015); inclusion of goal adjustment strategies in *practice recommendations* for use in diabetes primary care settings (Miller & Bauman, 2014), and finally, use of a *goal based assessment* and *targeted psychosocial support* for breast cancer survivors to help them cope with goal interference and associated distress (Stefanic et al., 2014).

***Patient centred versus staff led strategies or approaches to goal adjustment.*** Five percent ($n = 5/91$) of the included studies, all using qualitative methods, identified staff-led or patient-centred strategies or approaches to support goal adjustment (see Supplementary File 13). In staff led approaches (Barnard et al., 2010; Hunt et al., 2015; Leach et al., 2010), staff took ownership of patients' goals and either implicitly for example, moving on to the next goal, despite signs of patient resistance (Barnard et al., 2010) or explicitly for example, indicating that the goals are non-negotiable (Barnard et al., 2010) adjusted or disregarded them at the goal setting stage, without collaboration with the patient. This approach was taken to ensure goals were measurable, achievable and compatible with organizational constraints. In patient (or client) centred approaches (Fleming et al., 2013; Hunt et al., 2015; Lawler et al., 1999; Leach et al., 2010), staff used strategies to enable patients to maintain ownership of their goals and to ensure that any goals set, or adjustments made to them, were done collaboratively for example, advocating for clients and their goals and enabling their participation (Hunt et al., 2015).

***Stakeholder consultation.*** Following discussion and consideration of the interventions, strategies and approaches reported to support goal adjustment, stakeholders agreed that:

- *Strategies to support goal adjustment* are important for people with long-term conditions.
- *Psychological interventions* could be helpful, and should be considered, particularly for those who need additional help to adjust goals.
- *Rehabilitation approaches* should incorporate strategies to support adjustment of life goals

- *Education and training* could be helpful; especially the peer support aspect of group interventions
- *A patient-centred approach* should be adopted to support goal adjustment.
- *A staff-led approach* could be helpful; particularly if the process of setting and adjusting goals was new and the patient needed clear direction. However, staff-led strategies could be unhelpful, particularly if staff: (i) resisted discussion around goals to avoid adjustment, (ii) used their authority to dictate goal adjustment, and (iii) gave the impression that goals were non-negotiable.

## Discussion

This scoping review aimed to systematically locate, review and summarize available literature on goal adjustment for people living with long-term conditions in order to identify research gaps and consider implications for practice. Our findings will be discussed in relation to the mapping exercise, then each specific research question.

### *Mapping exercise*

The high volume and varied nature of articles included in this scoping review suggests that response options to unattainable goals, i.e., goal adjustment, disengagement and reengagement, are relevant to a broad range of people living with long-term conditions, and the health and social care staff delivering their care. Whilst we identified a high number of quantitative studies investigating associations between goal adjustment, disengagement and reengagement and recovery and wellbeing; only one study aimed to evaluate the effectiveness of an intervention to support adaptive use of response options using a randomized controlled trial. This paucity of evidence-based interventions is a clear evidence-practice gap that warrants further attention.

### *Synthesis 1 (RQ1): Is goal adjustment defined within the literature, and if so how?*

Definitions of goal adjustment, disengagement and reengagement within included studies were variable and included a range of underlying concepts. This is problematic given these terms (i) represent important goal options relevant to the recovery and wellbeing of people living with a wide range of long-term conditions and (ii) are relevant to health and social care staff working in diverse settings and the research community. Use of uniform terminology is a necessary prerequisite for a shared understanding of terms and

concepts used between relevant stakeholders (World Health Organization, 2001) and development of a cumulative evidence base (Scobbie & Dixon, 2014, 216). On the basis of our content analysis and stakeholder consultation, we have suggested that goal adjustment, "adjusting a goal to make it achievable," should be viewed as one of three available options when goal maintenance is no longer viable; the other options being goal disengagement "letting go of the goal" and goal reengagement "re-engaging in a meaningful, alternative goal." We have provided a uniform terminology that is accessible to, and can be used by, all relevant stakeholders including people living with long-term conditions, health and social care staff providing their care and the research community.

### *Synthesis 2 (RQ2): Is goal adjustment underpinned by theories, models or frameworks within the literature, if so which?*

Our findings highlighted a high number of diverse theories, models and frameworks reported to underpin goal adjustment. However, three stood out as having particular relevance and value based on the number of times reported within included studies: the Dual process model of assimilative and accommodative coping (Brandtstädter & Rothermund, 2002), the Goal adjustment model (Wrosch et al., 2003b) and Self-regulation theory (Carver & Scheier, 1998). Our findings suggest broadly consistent concepts/themes across all three, namely: (i) an underlying premise that people, through their life course, will inevitably face situations in which attainment of highly valued goals is threatened, (ii) that continued goal pursuit *and* goal adjustment or disengagement, with the subsequent option of reengagement, should be considered as potentially adaptive response options, (iii) recognition of a goal-performance discrepancy is likely to precede adjustment or disengagement from valued goals, and that (iv) maintaining emotional wellbeing is integral to all goal options.

Complex interventions require a coherent theoretical basis to inform what the key components of the intervention are, and how they are likely to influence outcomes (Medical Research Council, 2000, 2008; Moore et al., 2014). Although we have identified broadly consistent concepts across the three most commonly reported models and theory, many others were proposed that may enhance our understanding of the factors that influence, and explain the consequences of, goal adjustment, disengagement and reengagement.

Integration of psychological theory has been used to inform setting and achieving rehabilitation goals (Scobbie et al., 2009) and to enhance health behaviour change interventions (Hagger, 2009; Michie et al., 2008). Although beyond the scope of our review, further investigation of theoretical constructs across theories, models and frameworks relevant to goal adjustment may enhance theoretical integration within this topic area. This in turn could

inform development and evaluation of complex interventions seeking to support people with long-term conditions when attainment of their highly valued goas is threatened.

### *Synthesis 3 (RQ3): Is there evidence of an association between goal adjustment and recovery or well-being?*

Based on cross sectional and prospective cohort studies, our findings suggest that goal adjustment, disengagement and reengagement have a predominantly positive association with recovery and wellbeing in people with long-term conditions. A recently published meta-analysis, including 36 studies, quantified associations between goal disengagement and reengagement capacities with individuals' quality of life (Barlow et al., 2020). The authors reported that both goal disengagement and reengagement were associated with higher levels of psychological well-being and indicators of physical health. Although this meta-analysis did not investigate goal adjustment, or restrict its study population to people with long-term conditions, the findings provide further evidence to support the adaptive function of goal disengagement and reengagement when confronted with unattainable goals.

Whilst these findings suggest a positive association between goal response options and recovery and wellbeing, it is not clear if a causal relationship exists. Additionally, it is not clear which individuals are most likely to encounter difficulties making adaptive adjustments and what the optimal timing of such adjustments should be. For example, improving upper limb function or aphasia post stroke is likely to involve intense, repetitive practise (Brady et al., 2016; Pollock et al., 2014). Disengaging from goals prematurely may compromise optimal recovery in these areas. How do we know when flexible goal adjustment or disengagement is preferable to continued goal pursuit? These are important clinical questions that do not have clear evidence-based answers. Addressing this evidence-practice gap would help clinicians to target interventions, in a timely fashion, to those most at risk of compromising recovery and wellbeing due to difficulties making adaptive goal responses in the face of unattainable goals.

### *Synthesis 4 (RQ4): What interventions, strategies or approaches have been reported to support the goal adjustment process?*

We identified five interventions reported to support goal adjustment in people with long-term conditions. Only one of these (Self-system therapy) (Eddington et al., 2015) had been evaluated in a randomized controlled trial. This lack of evidence is surprising given the high number of included studies (i) reporting positive associations between goal adjustment, disengagement, reengagement and recovery and wellbeing, and (ii) interventions, approaches and strategies

suggested to support the goal adjustment process. This finding highlights an important evidence-practice gap. Health and social care staff have limited evidence to inform their clinical reasoning and intervention selection. Consequently, the support people with long-term conditions receive when goal attainment is threatened may be suboptimal, and their recovery and wellbeing compromised.

Evaluating the effectiveness of other interventions reported to support goal adjustment within our review – the Goal setting and Action Planning framework (Scobbie et al., 2011, 2013); SMARTER goal setting framework (Hersh et al., 2012); Right on Target (Arends et al., 2013, 2017, 2018) and the Health Through Activity programme (Lyons et al. 2018) could go some way to addressing this evidence-practice gap. Our findings also suggested candidate psychological interventions that may be worthy of further development and evaluation including – mindfulness; cognitive behaviour therapy, motivational intervening and acceptance and commitment therapy. In addition to these interventions, specific strategies reported by people with long-term conditions as being helpful could be incorporated into new or existing interventions. These research gaps represent fruitful areas for further research.

Finally, the integrated findings of our review and stakeholder feedback suggest that both patient centred and staff led approaches may helpfully support goal adjustment, disengagement and reengagement, as long as a collaborative approach is maintained. The importance of maintaining patient-centred goal setting approaches (and the challenges of achieving this) in rehabilitation settings has been emphasized (Rosewilliam et al., 2011; Sarah et al., 2016; Sugavanam et al., 2013). However, there is evidence to suggest that in the early stages of rehabilitation, patients often expect, and may benefit from, a therapist-led approach (Sarah et al., 2016). Our stakeholders agreed that staff led approach could be helpful. However, staff enforcement of goal adjustment (either covertly or overtly) without collaboration was not acceptable and likely to be unhelpful for people with long-term conditions. This is an important caveat. Our theoretical findings suggest that goal adjustment and disengagement is preceded by recognition and acceptance of a discrepancy between current and required goal performance (cognitive component) and that maintaining emotional wellbeing is integral to the process (emotional component). The interplay between goals, behaviour, cognitions and emotions has been well established (Bandura, 1997; Carver & Scheier, 1998; Hart & Evans, 2006; Jones et al., 2013; Siegert & Taylor, 2004; Siegert et al., 2004). From this perspective, the key to adaptive goal adjustment, disengagement and reengagement by people with long-term conditions, is the cognitive and emotional processes that underpin it. These processes may be less likely to occur if goal adjustment is enforced by staff. Consequently, opportunities to enhance recovery and wellbeing may be lost.

## Limitations

Although we are confident this review has been conducted to the highest standards, there are limitations that should be considered when interpreting the findings. Within a small number of studies including people with cancer, it was unclear from the reported data if participants had suffered from their condition for a year or more. In line with our pre-planned strategy of being inclusive, we decided to include these studies. Although this decision risked including studies with participants that did not meet our long-term condition criteria, we believe the numbers would have been so small that it would have been unlikely to alter our findings.

A second limitation of our review was that there was no assessment of the methodological quality of included studies. Consequently, we may have included data from studies of poor quality in our syntheses. Furthermore, we reported the nature of associations between goal adjustment and recovery and wellbeing variables, and outcomes of interventions to support goal adjustment (albeit it for only one study), without reference to statistical methods or results. Both limitations are inherent when using scoping review methodology. Given the nature of our overall aim and research questions, we are confident that this was the right approach to take. However, we acknowledge that different methods would be required to address research questions of a different nature, for example to report the predictive value of associations described or effectiveness of interventions reported.

We synthesized data across all included studies rather than within individual long-term conditions. The number of long-term conditions reported in included studies would have made condition specific synthesis impractical. However, there may be condition specific differences in the nature and course of goal adjustment, disengagement and reengagement that our review did not uncover. For example, people with long-term conditions affecting their cognitive function (for example, stroke or traumatic brain injury) may have difficulties realistically appraising their performance to make informed goal adjustment decisions. Furthermore, people with potentially life limiting conditions (for example, cancer) may have a different perspective on goal adjustment or require different interventions, strategies and approaches to support their psychological wellbeing and quality of life. We hope that highlighting this limitation will act as an impetus for further condition specific research in this area.

Finally, although we deliberately took a broad and inclusive approach to the literature in this scoping review, we did have to make final decisions about terms used within our staged search strategy, thus creating boundaries that we could practically work within. Whilst this was a necessary part of the scoping review process, our search strategy may have may have missed literature relevant to goal adjustment that used terms/concepts not included within our strategy.

## Conclusions

Goal adjustment, disengagement and reengagement are available goal response options when goal attainment is threatened. Although two models and one theory have been widely cited as underpinning these response options, further integration of constructs across reported theories, models and frameworks is warranted. Goal adjustment, disengagement and reengagement have a predominantly positive association with recovery and wellbeing in people with long-term conditions; but it is unclear whether a causal relationship exists. Although a patient-centred approach is likely to be helpful, there is a notable lack of evidence-based interventions to support people with long-term conditions when attainment of valued goals is threatened. Additionally, it is not clear which individuals are most likely to encounter difficulties when faced with unattainable goals, and what the optimal timing of goal adjustment or disengagement should be. These important evidence- practice gaps warrant further attention to ensure that people with long-term conditions receive the right support, at the right time, to optimize their recovery and wellbeing when faced with unattainable goals.

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